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AUTHOR	Jones, Doris; Miller, Susan; Medina, Catherine
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ABSTRACT

A study examined the degree to which families with disabled children in remote areas of the Navajo Reservation were aware of and used family support services. Twenty-five undergraduate students enrolled in special education teacher training courses designed, implemented, and assisted in data analysis. Interviews and surveys were completed by 89 parents, educators, and professionals from community agencies in the Kayenta Unified School District and the Pinon Unified School District (Arizona). Over 70 percent of the participants were Navajo. Separate surveys/interviews for educators, parents, and community agencies covered relationship to child; nature of child's disability; types, use, and availability of support services; referral practices; and support service eligibility. Results showed that parents were well informed of the services available to their children and were using the services. It appeared that collaboration between the school systems and various agencies facilitated awareness and use of services. Parents indicated a need for more organized activities for their children, a good working public library, and a parent newsletter. Includes survey/interview questions. (SAS)

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Ms. Doris Jones
Dr. Susan Miller
Dr. Catherine Medina
and the NAU Research Team*
Northern Arizona University
Flagstaff, AZ 86011-5774

PARENT SUPPORT SERVICES ON THE NAVAJO RESERVATION

Introduction

Facilitating support services is an essential part of providing assistance for the families of students who are disabled. Family support is defined as whatever resources are needed to increase the family's ability to care for their child, and improve the quality of life, while maintaining the child in their natural living environment . The goal in assisting families should be to maintain the family unit, improve the care giving ability of families, giving consideration to cultural and spiritual beliefs, while helping families to find and use the appropriate support services for their child who is disabled (Association of Retarded Citizens, 1992).

According to Debby Storey, of the Family Support Project in Kayenta, Arizona, examples of family support services can include, but are not limited to:

Respite care
Special Clothing
Crisis intervention
Cash subsidies
Information/referral
Vehicle modification
Family training
Diagnosis and evaluation
Home modifications
Transportation
Counseling
Behavior intervention
Medical/dental services
recreation

Working with the parents and guardians of children with disabilities in rural areas presents unique circumstances. Providing support services to parents in the remote areas of Kayenta and Pinon, Arizona, on the Navajo Reservation, requires creativity, persistence and determination for both the Kayenta Unified School District (KUSD) and the Pinon Unified School District (PUSD). The remoteness of KUSD and PUSD is not the only factor that impacts the delivery of parent support services. The ruralness of home sites, dirt roads, difficult access, linguistic and cultural considerations create distinctive challenges in meeting the needs of families with children who are disabled (Jones, Prater, Miller et al 1997).

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The total enrollment of KUSD as recorded in the 1997-98 school year is 2,867. According to home language surveys ninety-five percent of parents declare Navajo as the primary language spoken in the home. The total population of special education students in the Kayenta District is 173. It is estimated that 76 percent of students currently enrolled in special education have parents who stated Navajo is the primary language spoken in the home (Turl, 1998). The total enrollment of PUSD is 1,426. The number ofspecial education students is 106. Only 27 of the students enrolled in PUSD are not Native American.

The Navajo Nation covers approximately 24,000 square miles and includes the three states of Arizona, Utah and New Mexico. The Navajo Reservation is the largest reservation in the United States. Presently 200,000 of the 600,000 Navajos enrolled in the tribe reside on the reservation (Tsosie, 1990).

Purpose

The focus of this paper is the support services available to parents and guardians of students with disabilities within KUSD and PUSD on the Navajo Reservation. Support services for the parents and guardians in Kayenta and Pinon will be discussed.

Method

This study was conducted by students taking undergraduate special education teacher training courses in the Pinon Preparation Program (PPP) and the Rural Special Education Project (RSEP). Ten students are enrolled in the PPP and fifteen students are enrolled in RSEP. The students from these programs designed, implemented, and assisted in the data analysis of this study under the supervision of their instructors.

Forty-six interviews were conducted in person and 17 over the telephone. 26 surveys were hand distributed to individuals within the school districts. All but one parent had children enrolled in the KUSD or PUSD. All professional staff that worked in the KUSD and PUSD (counselors, administrators, special educators, classroom teachers) were all grouped as educators. The data includes information from over 30 parents, 30 educators and 20 professionals from community agencies. Over seventy percent of the participants in this study were Navajo.

Survey/Interview Questions for Educators

1. In which school do you work?
2. What is your current position and what is the age range of the children you are teaching or supervising?
3. What support services are available for the parents/guardians of children with disabilities?
4. How are parents/guardians made aware of what support services they may qualify for?
5. When are parents/guardians made aware of what support services they qualify for?
6. What outside agencies do you work with to provide services to the parents/guardians of students with disabilities?

7. How are parents referred to these agencies?
8. What additional services do you feel are needed in your community?

Survey/Interview Questions for Community Agencies

1. For which community agency do you work?
2. What is your current position?
3. What type of services does your agency provide?
4. What is the age range of the children you are providing services for?
5. How and when are the parents/guardians referred to your agency?
6. Describe how students with disabilities or parents/guardians qualify for services at your agency?
7. Are you aware of additional programs in the community for parent/guardians of students with disabilities?
8. What additional services do you feel are needed in your community?

Questions for Parents/Guardians

1. Are you a parent/guardian of a Navajo child with a disability?
2. If not the biological parents, how long have you been the caretaker of your child?
3. What is the nature of your child's disability?
4. What do you know about your child's disability?
5. Are you aware of the support services available to you as the parent/guardian of a child with a disability?
6. Will you provide us with three examples of services available to you or your child with a disability?
7. How are you utilizing these support services?
8. How did you become aware of these services (e.g., teachers, administrators, T.V., radio, other)?
9. What additional services do you feel are needed in your community?

Note: During the interviews, if the questions were not understood it was then restated in a simpler form or translated into Navajo.

Educator Responses

Of the individuals responding to question one (In which school do you work?) there were nineteen primary, ten intermediate, three middle and three high school teachers.

In response to question two (What is your current position?) about one-half of the teachers reported to be special education teachers, one facilitator for Arizona School for the Deaf and Blind (ASDB), one speech pathologist, five administrators, and the others were regular classroom teachers.

In response to question three (What support services are available for the parents/guardians of children with disabilities?) five educators indicated that they were not aware of what services were

available to the parents of children with disabilities in the area of Kayenta. One educator responded "no services" were available in Kayenta. Two educators responded with Student Intervention Team/Student Assessment Team (SIT/SAT) and three educators indicated "support" groups. However, the majority of educators listed services from the following: occupational therapy, physical therapy, assistance for hearing impaired students, assistance for visually impaired students.

In response to question four (How are parents/guardians made aware of what support services they may qualify for?) 25 of the educators stated that they relied on SIT/SAT to refer parents to support services. The remaining responses included such answers as parent newsletters, personal contact and personal visitation.

When educators were asked question five (When are parents made aware of the support services they qualify for?), two educators said parents were informed through school personnel. However, most all educators knew parents were informed by the schools' Special Education Department. There was one educator that did not know how the parents were informed of services while another did not know that parents of children with special needs were informed at all.

Responses to question six (What outside agencies do you work with to provide services to the parents/guardians of students with disabilities?) were as follows: six teachers reported they did not work with outside agencies, two responded "I don't know." The remaining educators' responses included the following agencies: Indian Health Services (IHS), Behavioral Health Services, Department of Developmental Disabilities (DDD), Social Services, Arizona School of the Deaf and Blind, and the Special Service Consortium.

The data for question seven (How are parents referred to these agencies?) revealed the following means of referral: the special education department, KUSD, SIT/SAT, and IHS. Three people surveyed responded with "I don't know".

Responses to question eight (What additional services do you feel are needed in your community?) were as follows: support services, parent education, community education and respite care services.

Responses from Community Agencies

Of the individuals responding to item one (For which community agency do you work?), they reported to be employed by the following agencies: IHS, Behavioral Health Services , John Hopkins University in conjunction with Behavioral Health Service, Social Services, Family Assistance and Food Stamps (FA/FS) the Department of Economic Security (DES), Women, Infants and Children (WIC), Kayenta Police Department (KPD), and Special Services Consortium.

In response to question two (What is your current position?) there were nurses, community health workers, clinical social workers, service coordinators, health systems specialists, physical therapy assistants, family therapists, caseworkers, police officers, community nutrition workers and a human resource manager.

The responses to question three (What type of services does your agency provide?) varied according to the role of the agency. IHS included medical care at the clinic, physical therapy, counseling, emergency room care, and community home nursing care. Behavior Health Services included group counseling, individual counseling and family counseling. Social Service stated that their main role was foster care placement and early intervention services, which includes coordination of services for children with special needs. The WIC nutrition specialist managed cases for pregnant women, and mothers of infants/children seeking WIC coupons. The DES included supplemental income assistance for families of disabled children. FA/FS included referrals for income assistance and food stamps. The KPD service included criminal investigation and law enforcement.

In response to question four (What is the age range of the children you are providing services for?) the IHS workers stated that they provided medical care for infants to the elderly, Behavioral Health Services worked with children between the ages of five through adulthood. The John Hopkins Research Nurse worked primarily with infants from six weeks of age until they were two years old. The Social Workers and Family Assistance and Food stamp workers indicated they worked with various ages from newborns through the elders of the community. The WIC nutritional worker indicated that WIC provided services for pregnant women and children ranging from newborn infants to five years of age. The KPD did not report specific ages.

Data collected for question five (How and when are the parents/guardians referred to your agency?) indicates a perception of cooperation with community agencies and expressed that referrals are made through a number of resources. These resources included: the women's shelter, DES, family courts, Child Rehabilitative Services, the IHS clinic, Behavior Health Services, KUSD, KPD and Social Services. The data also reflected that many people "self-referred" or were referred by a family member .

In response to question six (Describe how students with disabilities or parents/guardians qualify for services at your agency?) the majority of responses indicated that those children identified with disabilities or developmental delays were put in the system at birth by physician referral. Children who later qualified for disabilities sometime during their school care were referred by the school district, family courts, or IHS. The referral process for older children indicated qualifying by several means, physician recommendation or qualify by a parental/guardian interview process. One IHS nurse stated that, "IHS works with KUSD to supplement services the school district is unable to provide".

Predominant responses to question seven (Are you aware of additional programs in the community for parent/guardians of students with disabilities?) were, KUSD, WIC, Social Services, IHS, DES and Behavioral Health Services. An additional service mentioned was the Department of Developmental Disabilities (DDD).

Responses to question eight (What additional services do you feel are needed in your community?) were expressed as follows: Youth Center for Special Needs Day Care, Services for the Blind & Deaf, Parental Education Services, family support groups, parent resource information, transportation services for the disabled, and group homes for the disabled.

The information reported above on community services was collected in Kayenta. Due to the smaller population of Pinon, most of the support services are provided through the school district. There

is one small IHS office in Pinon, and the residents also receive services from the Chinle agencies, which are located about 45 miles from Pinon.

Responses from Parents and Guardians

All but one parent responding to question one (Are you a parent/guardian of a Navajo child with a disability) was Navajo, and all were parents of children with disabilities.

Responding to question two (If not the biological parents, how long have you been the caretaker of your child?) all participants stated they have been the primary caretaker for their child from birth.

The responses to question three (What is the nature of your child's disability?) were varied. Parents reported having children with learning disabilities, Down syndrome, mild mental retardation, visual impairments, deafness, autism, attention deficit/hyperactivity disorder, cerebral palsy, juvenile arthritis, Hunters disease, neuromuscular disorder, physical challenges, and developmental delays. One parent reported their child as gifted.

In response to question four (What do you know about your child's disability?) almost all parents clearly understood their child's disability, one knew little about their child's disability and one parent did not respond to the question. The majority of the parents/guardians were able to list more than five different characteristics/difficulties of their child. A few parents very confidently stated they knew all they needed to know about their child's disabilities.

In response to question five (Are you aware of the support services available to you as a parent/guardian of a child with a disability?) the vast majority of parents stated specific services available to them. Only one parent stated they were not aware of services and one parent said they knew of services available, but did not not use them.

Question six (Will you provide us with three examples of services available to you or your child with a disability?) responses indicated that parentswere aware of services available to them. Services that were frequently mentioned were ASDB, Parent Out Reach, IHS, and DDD.

According to the data collected for question seven (How are you utilizing these support services?) the most common response was that they were aware of and used services in their area. The majority of answers reflected that most of the services were obtained through the school district. Two most common services received outside of the school were IHS and DDD.

In response to question 8, (How did you become aware of these services (e.g. teachers, administrator, TV, radio, others?) most all parents responded that they became aware of available services through teachers, physicians, and school personnel.

In response to question 9, (What additional services do you feel are need in your community?) the parents interviewed gave various answers. The most frequently given responses were a monthly parent newsletter , Special Olympics or other organized activities, a good working public library or place they could do research.

Conclusion

The participants indicated that the two communities involved in this study are providing services for individuals with disabilities. For the most part, parents are well informed of the services available to their children and are using them. Also, it appears that collaboration between the school systems and various agencies is occurring to facilitate awareness and use of these services.

The parents did indicate a need to have more organized activities for their children or to be linked to other parents. We as educators need to constantly explore creative ways to involve these parents.

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*The NAU Research Team consists of the following: Beach, M., Begay, M., Begaye, D., Bitsui, S., Blie, L., Bob, L., Bob, S., Castillo, T., Crank, C., Delmar, B., Denny, V., Dixon, L., Dove, M., Dugi, R., Fuller, D., Gilmore, E., Gonnie, J., Grochowski, J., Hoskie, L., Manygoats, C., Montoya, E., Mullins, J. S., Jim, O., Singer, R., Snyder, M., Webb, R., Zonnie, T.,

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